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PAGE 2: Proposed Organ and Tissue Donation (Scotland) Bill Consultation

Q1: The overarching purpose of my proposal is to move from the current opt-in system to a soft opt-out system of organ donation. Do you support this move? Please indicate “yes/no/undecided” and explain the reasons for your response.

No,

Please give your reasons for your response:
As an intensivist involved in counselling relatives of patients being considered for organ donation I am concerned about this. There are clear cases when yes is the answer but for those undecided or clear refusal families, the idea that this process would go ahead despite their reservations is abhorrent. The pressure put upon families by careworkers and ultimately by society may mean decisions are made leading to long term regret. Whether protected by law or not, by introducing a form of mandatory submission for organ donation can lead to distress in some cases. We prefer the discretion allowed currently to permit time for discussion and full exploration of the facts if a family wishes to do so.

Q2: How essential is it to change the law (from an opt-in to a soft opt-out system) in order to achieve the intended benefits (increased transplant rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?

The waiting lists are only larger because of the increased referral rates which is not often talked about. We also pick up the pieces of failed transplants and of the increasing number of people on immunosuppression leading to life threatening sepsis. I dont think that the law needs to be changed when there is still work to be done in gaining donors from A&E depts and embedding training in these areas for example. The other problem is the provision of transplant teams who cannot and do not prioritise anything outwith the central belt and in Grampian we have had several incidents of donor not surviving while waiting for the team to arrive. Generally we are at the bottom of the list for arrival. Also the communication from transplant teams is abysmal and patronising. We could do much more with their help and guidance but inevitably we end up producing donors buyt the organs are not worth saving once they get here. By the way I am pro organ donation but not pro the way that NHSBT have gone about procuring more organs. There are better ways to do this and are reproducible in many centres.

Q3: I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree? Please indicate “yes/no/undecided” and explain the reasons for your response.

No,

Please give reasons for your response:
This can be a difficult time for a family and one should work hard to take them with you and not against them. I would not be surprised if this leads to legal action but where will NHSBT be then? It will be the frontline staff who get the consequences and I am concenred this can end careers if not allowed to work sensitively within the current framework.

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Q4: Do you think an individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes,

Please give reasons for your response:
BUT I do not think the man in the street is adequately informed about the process of organ donation in an unbiased way without parading successful recipients as a form of emotional blackmail. I don't think for example that there is an awareness of performing CPR on DCD patients and having to occlude the carotids to prevent them coming to or waking up. This I think would be a step too far for some members of the general public. Would the organ donation lobby be comfortable to allow this sort of knowledge to become common?

Q5: My proposal is that only adults should be automatically opted-in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent as they currently do. This approach is I believe the best way to safeguard children and young people. Do you agree? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes,

Please give reasons for your response:
And I have to say I find the information provided to schoolchildren is a shocking single sided view and a way to get them to sign up to the ODR - which many do with little consideration to how their parents may feel about it. Yes we all want to help someone after our death/ we are just a soul within a shell/ the person that we knew is no longer there but I see an erosion of autonomy especially of that of the family and again a lack of trust in clinicians to be able to inform a family correctly.

Q6: Do you agree the age limit for an adult should be set at 16 years old? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes

Q7: Do you agree the soft opt-out system should apply to people who have been resident in Scotland for a minimum period of 1 year prior to their death? Please indicate "yes/no/undecided" and explain the reasons for your response.

Undecided,

Please give reasons for your response:
I really do not know what threshold to use. There are many transient workers in Scotland - it is a difficult area.

Q8: If you answered no to the above how long, if any, should this period of residency last before they become subject to the soft opt-out system? Would this residency need to be for a continuous period?

Respondent skipped this question

Q9: Do you think 6 months is a long enough period to run a campaign prior to change over?

This sounds awfully like a fait accompli to me

Q10: What is your assessment of the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?

More donors and more people waiting for the increasingly busy transplant team unfortunately, therefore less organs being taken and more people dying prior to the process being completed. With current ICU provision in this hospital this will significantly stress us as we are already at breaking point. Perhaps some immeasurable increase in complaints and possibly lawsuits

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Q11: Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

Not sure but specific religious implications and guidance will have to be very carefully considered prior to the drawing up of the bill which will hopefully happen.

Q12: Do you have any other comments on or suggestions relevant to the proposal?

I dont think this is necessary but am powerless to stop it happening. I think this continues to burden a stressed healthcare system which has problems dealing with the living let alone the dying (I speak only for intensive care). With the appropriate increases in support, transplant teams, engagement of A&Es and protection of medical and nursing staff this may not be required but to 'chuck it in' is short sighted in the extreme. It would be great to look at some of the other aspects of intensive care provision (eg lack of nursing staff and staff development) first rather than adding to the burden of it with this.

PAGE 3: Contact Details

Q13: If you wish your response, or any part of it, to be treated as anonymous and/or confidential, please check the appropriate box. If not, then please go to question 14.

Anonymous

Q14: Thank you for completing this survey. Please provide your name and contact details below.

Name	x
Company	xx
Address	xx
Address 2	xx
City/Town	xx
State/Province	xx
ZIP/Postal Code	xx
Country	xx
Email Address	x